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Analysis Of the Relationship of Stigma to The Quality Life of Leprosy Patients

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ABSTRACT

Leprosy sufferers from a very high disease burden, those with disabilities become unproductive, unable to live independently to meet their needs. WHO defines quality of life as an individual's sense of their place in life within the framework of their culture, value system, and its link to life objectives, expectations, standards, and other relevant factors. Stigma against leprosy sufferers and even their entire families is still found in society. This is what makes most leprosy sufferers prefer to keep to themselves and avoid association with society because they are ashamed and afraid of their illness. So that it can affect the quality of life. Therefore, this study was conducted to analyze the relationship between stigma and quality of life. This study used primary data through interviews with 63 lepers with a cross-sectional study design using WHOQOL-BREF. The results of this study indicate that there is a relationship between stigma and quality of life for leprosy sufferers in Bone district with a p value = 0.000 < 0.05.

Keywords**:** Leprosy, Quality of Life, Stigma

INTRODUCTION

Leprosy is still a public health problem, the goal of leprosy prevention in Indonesia is to minimize the illness's burden by limiting disease transmission (Van Brakel et al., 2012; Narang & Kumar, 2019; Singh et al., 2019), avoiding impairment in all new patients discovered via adequate treatment and care, and eradicating social stigma in society. This is consistent with WHO's leprosy management strategy, which includes developing quality services for leprosy patients and reducing the disease's burden (Sarode et al., 2020; Maymone et al., 2020; Marahatta et al., 2018; Jung et al., 2020), which is accomplished not only by increasing early case detection but also by reducing disability, stigma, and discrimination, as well as social and economic rehabilitation for leprosy patients (Urgesa et al., 2022; Agarwal & Mishra, 2022). Because information concerning quality of life is critical (Ribeiro et al., 2018; Heritage et al., 2018; Skevington & Böhnke, 2018), there are several methods for attempting to assess a person's quality of life based on various facets of human existence. For example, the World Health Organization (WHO) attempted to develop a measuring tool/instrument to assess the quality of human life known as the World Health Organization Quality of Life 100 and its abbreviated form, the World Health Organization Quality of Life-BREF (WHOQOL-BREF).

This instrument attempts to assess the quality of human existence across several domains, including physical, psychological, social, and environmental factors (Utian et al., 2018; Leiler et al., 2019; Ribé et al., 2018). This tool has been extensively utilized for a variety of disorders, including determining the quality of life of leprosy patients (Guimenes et al., 2019; Van't Noordende et al., 2020). Measuring the quality of life of leprosy sufferers is expected to be the basis for consideration in intervention and management of leprosy problems which are not only focused on physical recovery but also need to pay attention to other factors that can lead to a decrease in the quality of life of leprosy sufferers. Factors related to the quality of life of leprosy patients can be viewed from leprosy disease and demographic characteristics (Das et al., 2020; Xiong et al., 2019; Govindharaj et al., 2018).

METHODS

This research was conducted in April-June 2020. The research location was carried out in 27 sub-districts in Bone Regency using the WQOOL-BREEF quality of life format with a cross sectional study approach.

RESULTS

Respondent Characteristic Descriptive

The respondent's characteristic is the respondent's intrinsic trait. In this study the characteristics of the respondents displayed included age, gender, occupation, education, marital status and type of leprosy.

Table 5.3.
Characteristics of Respondents

Respondent Characteristic	Frequency	Percentage
Age		
<25	1	1.6
25-29	4	6.3
30-34	9	14.3
35-39	10	15.9
>40	39	61.9
Total	63	100.0
Gender		
Male	39	61.9
Female	24	38.1
Total	63	100.0
Education Level		
Never went to school	3	4.8
Not completed in primary school	20	31.7
Finished elementary school	25	39.7
Graduated from junior high school	5	7.9
Graduated from high school	10	15.9
Total	63	100.0
Profession		
Doesn't work	17	27.0
Entrepreneur	18	28.6
Farmer	28	44.4
Total	63	100.0
Marital Status		
Married	52	82.5
Not Married	11	17.5
Total	63	100
Leprosy Type		
PB (*Pausible Basiler*)	18	28.6
MB (*Multi Basiler)*	45	71.4
Total	63	100.0

Based on table 5.3 below, it shows that the distribution of respondents by age with the highest age frequency was in the age group >40 years of (61.9%) and the lowest age frequency was in the age group <25 years of (1.6%). Based on gender, there were more male respondents (61.9%) and female (38.1%). Based on the level of education, the respondents showed more at the elementary school level of education (39.7%), and the lowest was that the respondents did not attend school (4.8%). Most of the respondents worked as farmers (44.4%), while the lowest were respondents who did not work (27.0%). In marital status, more respondents were married (82.5%) and unmarried (17.5%). The type of leprosy respondents was more MB (Multi Basiler) by (71.4%), and PB (Pausible Basiler) by (28.6%).

Table 5.4.
Distribution of Respondents Based on Quality-of-Life Research Variables of Leprosy Patients

Life Quality	Frequency	Percentage
Good	27	42.9
Not Good	36	57.1
Total	63	100.0

Table 5.4 shows that most lepers have a poor quality of life (57.1%), while a good quality of life is (42.9%).

Table 5.5.
Distribution of Respondents Based on Quality-of-Life Domain Research Variables of Leprosy Patients in Bone District

Quality of Life Domains	Frequency	Percentage
Physical Domains		
Good	29	46.0
Not Good	34	54.0
Total	63	100.0
Psychic Domains		
Good	21	33.3
Not Good	42	66.7
Total	63	100.0
Domain of Social Relations		
Good	23	36.5
Not Good	40	63.5
Total	63	100.0
Environmental Domains		
Good	26	41.3
Not Good	27	58.7
Total	63	100.0

Based on table 5.5, it shows that of the four domains, the average quality of life is not good, from the physical domain, there are more that are not good (54.0%) while good are (46.0%). There are more psychic domains that are not good (66.7%) while they are good (33.3%). the domain of social relations is more unfavorable (63.5%) while good (36.5%). Environmental domains are more unfavorable (58.7%) while good (58.7%).

Table 5.6.
Respondent Distribution Based on Independent Factors.

Variables	Frequency	Percentage
	Stigma	
With Stigma	44	69.8
No Stigma	19	30.2
Total	63	100.0

Based on the table above, it was obtained from 63 respondents that there was a stigma of (69.8%) and no stigma of (30.2%).

Table 5.7.
Distribution of Independent Variables on the Physical Domain of Leprosy Patients in Bone District

Independent Variable Stigma	Physical Domain			
	Good		Less Good	
	Frequency	Percentage	Frequency	Percentage
With Stigma	14	31.8	30	68.2
No Stigma	15	78.9	4	21.1
Total	29	46.0	34	54.0

Based on the stigma of respondents who have a good Physical Domain (48.3%) who have stigma, and those who do not have stigma (51.7%).

Table 5.8.
Distribution of Independent Variables on Psychological Domains of Leprosy Patients in Bone District

Independent Variables Stigma	**Psychological Domain**			
	Good		**Less Good**	
	Frequency	**Percentage**	**Percentage**	**Frequency**
With Stigma	13	61.9	31	73.8
No Stigma	8	38.1	11	26.2
Total	21	100.0	42	100.0

Based on the study's findings, it was discovered that there were 21 respondents who had a good Psychological Domain (61.9%) who had stigma, and those who did not have stigma (38.1%).

Table 5.9.
Distribution of Independent Variables to the Domain of Social Relations of Lepers in Bone District

Independent Variables Stigma	**Social Relations Domain**			
	Good		**Not Good**	
	Frequency	**Percentage**	**Frequency**	**Percentage**
With Stigma	15	65.2	29	72.5
No Stigma	8	34.8	11	27.5
Total	23	100.0	40	100.0

Based on the table above, from 40 respondents, it was found that there were 23 respondents who had a good Social Relations Domain (65.2%) who had stigma, and those who did not have stigma were 11 respondents or (34.8%).

Table 5.10.
Distribution of Independent Variables to the Environmental Domain of Leprosy Sufferers in Bone District

Independent Variables Stigma	**Domain Environment**			
	Good		**Less Good**	
	Frequency	**Percentage**	**Frequency**	**Percentage**
With Stigma	13	50.0	31	83.8
No Stigma	13	50.0	6	16.2
Total	26	100.0	37	100.0

Based on the study's findings, it was discovered that there were 13 (50.0%) of the good Environmental Domains who had stigma, and 13 (50.0%) of respondents who did not have stigma.

Bivariate Analysis

Table 5.11.
The relationship of independent variables to the quality of life of Leprosy Patients in Bone Regency

Independent Variable Stigma	**Life Quality**				**X^2**	**p Value**
	Good		**Less Good**			
	Frequency	**Percentage**	**Frequency**	**Percentage**		
With stigma	11	40.7	33	91.7	18.997	0.000
No Stigma	16	59.3	3	8.3		
Total	27	100.0	36	100.0		

Table 5.11 shows the distribution of leprosy sufferers who have good and poor quality of life. Based on stigma, it shows that of the 27 respondents who have a good quality of life (40.7%) who have a stigma, and those who do not have a stigma (59.3%). According to the findings of statistical tests, the computed X squared value = 11,997 > X squared table = 3.84 or with a p value = 0.000 < 0.05, so that H1 is accepted and H0 is denied, indicating that there is a stigma association to the quality of life of leprosy victims.

DISCUSSION

The Link Between Stigma and Leprosy Sufferers' Quality of Life

Stigma as an attribute that is highly discredited and Someone who is stigmatized is someone who is not accepted by his community and does not get respect, rights, or approval, or someone who is not socially acceptable (Taylor et al., 2020; DeFreitas et al., 2018; Vassli & Farshchian, 2018). Stigma has a strong social and psychological impact on every individual affected by the disease (including family members) and the community in which they live (Van't Noordende et al., 2020). This disease carries a significant stigma in the form of a community response to fear, rejection, insensitivity, condescension to those affected by the disease which in turn the community feels threatened by their presence. Based on this, it is clear that stigma has a significant impact on the degree of self-confidence of someone suffering from the condition (Bukhari et al., 2019; Li, 2020; Davern & O'Donnell, 2018). Especially for individuals who have leprosy, which is thought to be a cursed condition by the general public. As a result, sufferers are extremely embarrassed and fear that they will be treated differently as a result of this disease, including being ostracized by the environment, losing a job, being humiliated due to physical condition, and being forced to separate or be separated from a partner or family due to leprosy (Sottie & Darkey, 2019; Somar et al., 2020).

The results showed that the distribution of respondents from a good quality of life based on the existence of stigma (40.7%) and no stigma (59.3%), while judging from the poor quality of life (91.7%) there was stigma and (8.3%) there was no stigma. The results of the distribution above show that the more sufferers get stigma from the surrounding environment, the more they will affect their quality of life. Based on the findings of statistical tests, it may be concluded that H1 is accepted and H0 is rejected since the computed X squared = 11,997 > X squared table = 3.84 or with a p value = 0.000 0.05. indicating that there is a link between leper quality of life and family support. This study is consistent with that of Rahayuningsih (2012). Stigma and leprosy patients' quality of life were significantly correlated in 2012, with a value of p = 0.008. According to the study's findings, leprosy patients have a poorer quality of life than the general population at 57.45%. According to study done by 42.5% of people, their quality of life is not very excellent (Tang & Wu, 2012) He found that someone who is depressed with significant stigma has a terrible quality of life in his study, "Association between quality of life and self-stigma, insight, and side effects of medicine in patients with depressive disorders.

"Stigma greatly influences the quality of life of sufferers, especially leprosy sufferers who experience disabilities. The factors associated with stigma are disabilities. According to Bainson KA and Van Den Born B (1998) in their book Dimensions and Process Stigmatization, disability significantly contributes to the presence of leprosy stigma. They suggest that the stigma for leprosy victims in society is connected to the disability produced by leprosy. Although leprosy rarely causes death, the increasingly severe disability makes other people who see it fearful. As a result, even though leprosy sufferers have been medically treated and declared cured, if they are physically disabled, the predicate of leprosy will always be attached to their life, so that the surrounding community will shun the sufferer and their family (Akehurst, 2021). The stigma felt by leprosy sufferers is generally still very high. Until now, in Indonesia the stigma still exists and especially in Bone Regency this stigma still exists in the community. The general populace is aware of the leprosy sickness. In the past, residents of Bone Regency thought that this illness was brought on by supernatural forces, such as sorcery or a curse, and some even held the opinion that karma was to blame. Leprosy patients are thus frequently shunned by the community and even expelled from the area. For sufferers of this disease is a disease that is very embarrassing, so closing oneself is the only way, embarrassment to be known by other family members let alone spread in society. Unnatural anxieties frequently surface, such as the worry of being forcefully separated from their spouse or of being abandoned by their family because they are humiliated that a family member has leprosy.

CONCLUSION

Leprosy sufferers sometimes conceal their status as lepers and are hesitant to consistently seek treatment at health facilities, according to the statement that the stigma of leprosy is another issue that delays patients in receiving treatment. This situation does not support the process of treatment and recovery, on the contrary it will increase the risk of defects for the sufferer himself. Numerous misconceptions and falsehoods concerning leprosy have a significant impact on the stigma that exists in society, which has a severe impact on how others see and treat those who have the disease. Leprosy according to the belief of some Bone people is a cursed disease, and the status of a leper is a very heavy burden. Sufferers are afraid of getting a bad stigma in the form of different treatment in their environment, so even for treatment at the puskesmas they are still trying to cover up this disease from other people, and treatment of this disease can be slow and even fatal because the stigma that sufferers feel causes a decrease in quality of life. The stigma felt by sufferers is a very disturbing condition, because it can cause stress, emotional, anxiety, depression, and even suicide attempts. However, acceptance of sufferers in the community causes sufferers to have a higher level of trust and get rid of more stigma from within. Government programs on eliminating discrimination and negative stigma against sufferers have led to very good self-acceptance of sufferers in society, without any differential treatment so that it helps build the self-confidence of sufferers and helps the quality of life of leprosy sufferers to be good.

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